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TITLE: Relationship of Stress Exposure to Health in Gulf War

Veterans

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Standard Form 298 (Rev. 2-89) Prescribed by ANSI Std. 239-18 298-102

#### **Table of Contents**

Appendix C.	Lead letters/consent forms for Gulf War Follow-up Survey	************	•••
Appendix B.	Gulf War Veterans Follow-up (Mail) Surv	ey	: ■■1 <sup>2</sup> <sub>2 ma</sub> 2 =
Appendix A.	Data Form for Tenth Annual Gulf War Ve Health Survey telephone prompt	terans	. 1 750.8
Appendices			11
			1 1
Reportable Outcom	es	- - - -	11
Key Research Acco	mplishments		11
20uj			3
Body			E
Introduction		********	4
Table of Contents	***************************************		3
SF 298		******	2
Cover		************************************	1

#### Tenth Anniversary Gulf War Veterans Health Study

Progress Report: 1 October 2001 – 30 September 2002

#### INTRODUCTION: Brief Narrative of Subject, Purpose, and Scope of Research

Study Aims. Research on Gulf War (GW) illnesses leaves many questions unanswered about diagnostic syndromes of GW illnesses, dimensions of stressor exposures encountered by GW veterans, relations among stressor exposures and GW syndromes or symptoms, and factors that may mediate these relationships. This study has five key aims intended to address these gaps and enhance understanding of illnesses reported by GW veterans. These aims are:

- (1) to identify and examine dimensions of illnesses and health problems commonly reported by GW veterans;
- (2) to assess exposures to environmental toxins and psychosocial stressors comprehensively and to identify the dimensions of these exposures;
- (3) to examine the extent to which particular types of dimensions of exposure experienced during deployment and participation in Operation Desert Shield/Desert Storm (ODS/S) are associated with the commonly reported and undefined post-war health problems of GW veterans;
- (4) to clarify how premilitary and predeployment adversities, risk factors, and protective factors affect GW illness outcomes;
- (5) to examine the mediating role of post-ODS/S factors (e.g., instrumental and emotional social support, general psychological functioning, specific comorbid psychiatric disorders, such as posttraumatic stress disorder and depression) on GW illness outcomes.

Original Scope of Work. Originally, the aims of the Tenth Anniversary Gulf War Veterans Health Study were to be achieved using a two-phase study design. Phase 1 of the study was a mail survey of a national probability sample of GW veterans, including both men and women in active and reserve components. The goal of this survey was to provide comprehensive probability-based data about the dimensions of Gulf War illnesses, dimensions of exposure to environmental toxins and psychosocial stressors encountered by GW veterans, and relationships between these exposures and GW illness syndromes. These issues, as well as factors that may mediate relationships between stressor exposures and GW illnesses, were to be examined further in Phase 2 of the study, a computer-assisted telephone interview (CATI) conducted with a subsample of mail survey respondents with and without symptoms of GW illnesses.

#### Revisions to Scope of Work.

<u>DAMD17-98-8662</u>, <u>Mod P0003</u>. A no-cost extension was granted in DAMD17-98-8662, Mod P0003 extending the time frame for completing the Tenth Anniversary Gulf War Veterans Health Study to 10/31/03.

<u>DAMD17-98-8662</u>, <u>Mod P0002</u>. A revised scope of work was executed in DAMD17-98-8662, Mod P0002 on 6/26/2001. The revised protocol involved:

(1) modification of the study's incentive structure and procedures to improve response rate; and

(2) incorporating into the mail survey the key aspects of the CATI telephone interview formerly referred to as Phase 2.

Despite efforts to enhance the response rate to the Tenth Anniversary Gulf War Veterans Health Survey using state-of-the-science methods, we received completed surveys from only about 5100 veterans for a response rate of just over 50%. This response rate was higher than that typically achieved for mail surveys of military populations of comparable length (e.g., the 1998 Department of Defense sponsored Total Forces study obtained a response rate of 38%; the Naval Health and Research Center's 1995 Perceptions of Wellness and Readiness Study obtained a response rate of 36%). Nonetheless, the scientific and public controversy regarding the nature and etiology of Gulf War illnesses is such that we felt that it was critical for us to be able to empirically address questions about the effects of nonresponse on findings from this study. Therefore, during the current funding period we conducted a nonresponse follow-up with a subgroup of the sample for the Tenth Anniversary Gulf War Veterans Health Study that was nonresponsive to the initial mail survey. An overview of the procedures and results of this nonresponse follow-up, the Gulf War Veterans Follow-up Study, is provided in the body of this report.

#### PROGRESS REPORT (BODY OF REPORT)

This section describes the research activities and accomplishments toward achieving the approved statement of work.

#### Data Collection and Related Activities.

#### Tenth Anniversary Gulf War Veterans Health Survey

Below we describe data collection and related activities for the Tenth Anniversary Gulf War Veterans Health Survey (i.e., the initial mail survey) occurring subsequent to the submission of the Year 3 Progress Report. Data collection for the Gulf War Veterans Follow-up Study (i.e., the nonresponse follow-up to the initial mail survey) are described in a separate subsection.

- 11/5/01: Second copy of the Tenth Anniversary Gulf War Veterans Health Survey mailed by National Computer Systems (NCS) to sample members who were nonresponsive to the first survey mailing for whom we had potentially valid mailing addresses. The second survey mailing included an informational sheet explaining why the survey did not make reference to the September 11, 2001 terrorist attacks.
- 10/25/01-12/9/01: Conducted tracing of sample members whose surveys were returned to NCS as undeliverable subsequent to the time that the address file for the second survey mailing was prepared. (All tracing activities for this study were conducted by RTI's tracing unit.)
- 12/10/01: Provided NCS with updated address file to be used in third survey mailing for sample members with previously incorrect address information for whom tracing efforts yielded a potentially valid mailing address.
- 12/11/01-1/8/02: Engaged in a variety of activities to prepare for conducting telephone prompts to encourage sample members to complete and return their mail surveys. These activities included:

- Conducting batch searches in an effort to identify telephone numbers for sample members from whom we had not yet received a mail survey. (The IRS address file provided by NIOSH that was used to locate sample members did not include telephone numbers.)
- Developing forms and procedures for RTI's Telephone and Internet Operations Unit to conduct telephone prompts. (A sample of the primary data form for the telephone prompts is included in Appendix A.)
- Training telephone interviewers to conduct and log telephone prompts.
- 12/31/01: Third copy of the Tenth Anniversary Gulf War Veterans Health Survey mailed by NCS to sample members with potentially valid mailing addresses who were nonresponsive to the first and second survey mailings. Sample members who were not currently on active duty received a \$20 gift card with the third survey mailing. (As noted in previous progress reports, Active Duty Military are not permitted to receive incentives for participating in governmentsponsored surveys.)
- 1/9/01-1/27/01: RTI's Telephone and Internet Operations Unit attempted to reach sample members from whom we had yet to receive a Tenth Anniversary Gulf War Veterans Health Survey to encourage them to complete and return their surveys. RTI also resent surveys to sample members who expressed a desire to participate, but indicated that they had not received or had discarded their survey. Of the 5232 sample members we attempted to contact, telephone interviewers were able to speak directly with just over 1700 (32.5%) veterans, the vast majority of whom (90%) indicated that they would or might participate in the study. Telephone interviewers left voice mail messages requesting participation for an additional 858 sample members (16.4%). Unfortunately, there were many veterans whom we were unable to contact because the batch searches used to identify telephone numbers for these calls yielded incorrect numbers for nearly one third of the sample.
- Data collection for the Tenth Anniversary Gulf War Veterans Health Survey was completed in March 2002. Table 1 provides a summary of case status for the study sample at the end of this data collection. Note that because we are still cleaning these data, the numbers provided in Table 1 are approximate. According to these data, 51.9% of those eligible and alive at the time of data collection returned a completed questionnaire.

Table 1. Status of study sample upon completion of Tenth Anniversary Gulf War Veterans Health Survey

	_N_	% total
Total sample	10,301	100.0
Ineligible (did not serve in Persian Gulf		
Theater between 8/90 and 7/91) <sup>1</sup>	409	4.0
Deceased	83	0.8
Refused	224	2.2
Incapacitated	3	0.03
Incarcerated	.1 : .	0.01
Questionnaire not completed (includes sample	V 4	Ĺ.
members who could not be located)	4,485	43.5
Questionnaire completed & eligible	5,096	49.5
		1 7 7

For purposes of this study, only military personnel who served in the Persian Gulf Theater between August 1990 and July 1991 (i.e., during Operation Desert Shield/Desert Storm) were eligible for participation. We drew a sample of 10,301 rather than 10,000 because our contacts at the Defense Manpower Data Center indicated that 2-5% of those in the sample frame would not meet this criterion.

#### Gulf War Veterans Follow-up Study

A key aspect of this research was the inclusion of a national probability sample of Gulf War veterans. Because of the lower than expected response rate to the Tenth Anniversary Gulf War Veterans Health Survey we felt that it was imperative to make every effort to determine the representativeness of the study sample. Therefore, after careful consideration, we decided to conduct a nonresponse follow-up with approximately 1000 sample members who did not response to the initial mail survey. Key activities for this nonresponse follow-up, the Gulf War Veterans Follow-up Study are outlined below.

- 3/4/02-4/5/02: Development of sampling plan. Met with RTI sampling statisticians to determine the appropriate sample size for the nonresponse follow-up taking into consideration both scientific and fiscal issues. Once a target sample size of 1000 was determined, we worked with sampling statisticians on the project team to develop an effective sampling algorithm for the nonresponse follow-up. The nonresponse sample was selected to oversample strata with lower response rates to the mail survey. To protect sample members' rights as human subjects, veterans who explicitly refused participation in the mail survey were not included in the nonresponse sample.
- 4/1/02-6/7/02: Development and testing of instrumentation. After careful consideration and consultation with RTI's survey specialists, we concluded that in order to obtain adequate participation the instrument for the Gulf War Veterans Follow-up study needed to be briefer than the initial mail survey and be administered in an interview format. Because the cost of conducting face-to-face interviews was prohibitive, we chose to conduct the nonresponse follow-up using computer assisted telephone interviews (CATI). In an effort to obtain key information about the characteristics of the veterans who did not complete the initial mail survey while minimizing respondent burden, we selected from the mail survey items that would provide a broad assessment of the veterans' health status. Questions that gathered basic information about military service in the Persian Gulf (e.g., regions of service) and demographics also were included. Where necessary selected items were modified for interview administration, after which CATI specifications were drafted. These specifications also included scripts for confirming that the respondent met eligibility criteria for the study and scripts for obtaining informed consent. Once the CATI specifications were completed, the CATI program was written and tested extensively over a period of several weeks.
- 4/8/02-4/12/02: Development of incentive procedures. An incentive plan for the Gulf War Veterans Follow-up Study was designed taking into account (a) data from previous RTI studies indicating that only substantial increases in incentives were effective in a nonresponse follow-up, (b) input from RTI survey specialists emphasizing the benefit of providing a token of appreciation in advance of study participation, and (c) budgetary considerations. Thus, the incentive procedures for the Gulf War Veterans Follow-up Study included a \$5 gift card that was sent with the lead letter for the study. As indicated in the lead letter, the value of this gift card was increased by \$30 upon completion of the study. As in the initial mail survey, sample members identified as Active Duty Military were not offered incentives.
- 4/15/02-5/15/02: <u>Human subjects approval</u>. A protocol and consent forms for the Gulf War Veterans Follow-up study were drafted and submitted to the Institutional Review Boards (IRB) and Duke University Medical Center and RTI. No veterans were contacted about the Gulf War Veterans Follow-up study until IRB approval was obtained from both institutions.

- 4/16/02-9/30/02: <u>Tracing operations</u>. Prior to the start of data collection for the nonresponse follow-up, RTI's tracing unit attempted to identify valid telephone numbers for any nonresponse sample member whose telephone number was not confirmed during the telephone prompts for the initial mail survey. Using this approach, potentially valid telephone numbers were identified for just under 75% of the veterans selected for the nonresponse follow-up. Upon learning that we did not have telephone numbers for nearly one-quarter of the nonresponse sample, we developed a hard copy version of the nonresponse survey to send to those individuals. (This procedure was approved by DUMC and RTI IRBS. A copy of the nonresponse mail survey is included in Appendix B.) Intensive tracing continued on a flow basis throughout data collection as contact information for nonresponse sample members was found to be incorrect.
- 4/16/02-7/26/02: Development and distribution of lead letters, hard copy surveys, and related documents. Lead letters were developed for distribution prior to CATI data collection. Consent forms to accompany the mailing of hard copy follow-up surveys also were developed. Both sets of documents were reviewed and approved by the DUMC and RTI IRBs. (Sample lead letters/consent forms are provided in Appendix C) Lead letters and hard copy survey mailings were distributed between 6/3/02 and 6/7/02. Approximately, six weeks after this mailing, postcards encouraging participation were distributed to nonresponse sample members who were sent hard copy surveys.
- 5/15/02-6/11/02: Telephone interviewer training. Procedures and materials were developed and compiled into a training manual for training interviewers in RTI's Telephone and Internet Operations (TIO) Unit to conduct the Gulf War Veterans Follow-up Study CATI. A four hour training session for interviewers and TIO supervisory staff was conducted on 6/8/02, at which time staff received a copy of the study training manual. Between 6/9/02 and 6/11/02 telephone interviewers conducted (mock) practice interviews, continued CATI testing, and were certified. Ongoing supervision was provided by project staff and TIO supervisors. A toll-free number that sample members could use to contact RTI to schedule an interview also was activated at this time.
- 6/12/02-10/4/02: <u>Data collection</u>. Data collection for the Gulf War Follow-up Study began on 6/12/02 and continued through 10/4/02. We had originally planned on an eight to ten week data collection period; however, locating accurate telephone numbers for nonresponse sample members proved to be more difficult than we had expected, resulting in delays sue to the need for intensive tracing on an ongoing basis. Because of particular difficulties locating Active Duty sample members, we also requested an updated locator file from DMDC, after which we pursued new leads via telephone, US mail, and e-mail. Table 2 provides a tentative summary of case status for the nonresponse sample at the end of data collection. (A final review of case status for the nonresponse sample is still in progress.) According to these data, 52.8% of nonresponse sample members who were eligible for participation completed the follow-up CATI or a hard copy questionnaire.

<sup>&</sup>lt;sup>2</sup> No veteran was contacted directly to confirm a telephone number for the nonresponse follow-up until the study received IRB approval.

**Table 2.** Status of nonresponse sample upon completion of Gulf War Veterans Health Follow-up Study

Total sample <sup>3</sup>	<u>N</u> 987		% total 100.0
Ineligible (did not serve in Persian Gulf	\$		
Theater between 8/90 and 7/91)	17	;	1.7
Deceased	2	:	0.2
Refused (includes refusals by household			
members)	97	;	9.8
Incapacitated	3		0.3
Tracing unit unable to locate (address		,	
or telephone number)	 128	1	13.0
Follow-up survey not completed <sup>4</sup>	229		23.2
Hard copy follow-up survey completed	45		4.6
Follow-up CATI completed	466	. !	47.2

#### Data Editing and Analysis.

#### Data Editing/Cleaning

During the past year a number of data cleaning activities were conducted to prepare the data for analysis. The first step was to create datasets from each of the transmissions and then merge these into a single SAS dataset. New variables were created to be able to identify each transmission in the new file. This dataset was the starting point for a number of data cleaning activities.

- Fictitious records created to test data transmission were identified and deleted from the data file.
- Consistency and flow checks were conducted using SAS to check response patterns and, where applicable SAS program code was written to correct incorrect skip patterns.
- New variables were created for dates to utilize SAS date formats that will facilitate the use of these variables in analyses. Consistent code was developed to deal with problematic response patterns to these variables.
- SAS program code was created for a number of other derived variables (e.g. participants' phone numbers were treated as 10 individual variables by the scan program).
- Variable labels and SAS formats were created for the more than 200 variables to facilitate and help provide consistency in the analysis phase.
- Frequency tables were generated for all variables and examined to determine the extent of missing information. The impact of codes that indicate multiple response options were endorsed was also assessed.

<sup>&</sup>lt;sup>3</sup> We received completed Tenth Anniversary Gulf War Veterans Health Surveys from 13 veterans after the sample for the nonresponse follow-up had been selected, reducing the size of the nonresponse sample from 1000 to 987.

<sup>&</sup>lt;sup>4</sup> Includes Active Duty Military who were out of the country and for whom contacts could not or would not provide an address or phone number.

- Manual checks of the electronic copies of surveys were conducted in an effort to resolve multiple response codes. Where possible, response information was corrected or otherwise recaptured. This process included:
  - A direct recode with the correct response if the multiple response code was determined to be an error. Examples include: the scan program counted a stray mark as a valid response; the participant endorsed two items but clearly indicated that one response was in error.
  - Creation and implementation of consistent decision rules for some questions that select one of the multiple responses. Examples include: if endorsed both the active and reserve component of a military branch and the study identification number matches the reserve sampling stratum then recoded from multiple response to the reserve component of that branch; if endorsed both "no" to a question regarding pregnancy complications and "have not had or fathered children" recode from multiple response to "have not had or fathered children".
  - Development of new variables that captured information regarding all responses. For example, question 3 asks respondents to select the area of the Persian Gulf Theater where they spent the most time. While most items had between 0 and 6 multiple response codes, this question had a large number of multiple responses. Rather than lose this information completely for the 201 respondents who coded more than one response, a new set of dichotomous variables was created for each location.
- Scoring algorithms have been developed for all established measures that were used in the study (e.g. Hopkins Symptom Checklist-25; SF-36; Alcohol Use Disorders Identification Test). The corresponding program code for all scale and sub-scale scores has been written.

#### Data Analysis

Literature review has been updated to include most recent published studies. This update has
also focused on analytic strategies employed to identify symptom profiles and/or clusters that
could be indicative of Gulf War symptoms and on the rates of symptoms reported in the
literature by study population.

#### Schedule Projections.

10/31/02 - Received approval of a 1-year no-cost extension (DAMD17-98-8662, Mod P0003).

Activity	Months
Obtain study sample file from the Defense Manpower Data Center (DMDC; request	30
for sample submitted on 12 March 2001)	completed
Apply for and obtain clearance for revision to study incentive procedures and	30-31
protocol from the USAMRMC Human Subjects Committee and Contract Specialist.	completed
Apply for and obtain clearances for revisions to study incentive procedures and	30-31
protocol from the DUMC and RTI IRBs	completed
Submit request for current addresses of study sample to National Institute of	30-31
Occupational Safety and Health (NIOSH); obtain address file from NIOSH.	completed
Edit address file and send to National Computer Systems to format for mailing of	32
survey and related materials.	completed

Conduct and complete survey data collection activities	33-38
	completed
Plan and develop procedures for data editing and data analyses	33-38
	in progress
Edit survey data and develop analysis weights	39-40
	in progress
Construct analytic variables and conduct preliminary analyses.	40-43
	in progress
Conduct main analyses of survey data	44-48
Present study findings at scientific meetings and prepare article-length manuscripts.	48

#### KEY RESEARCH ACCOMPLISHMENTS

This section of the report focuses on "key research accomplishments emanating from the research." Data collection has only just been completed, therefore there are no accomplishments emanating from the research to report at this time.

#### REPORTABLE OUTCOMES

This section of the report summarized the results of the completed research. There are no reportable outcomes at this time.

#### **APPENDICES**

This report includes three appendices—Appendix A: Data Form for Tenth Anniversary Gulf War Veterans Health Survey telephone prompts, Appendix B: Hard copy Gulf War Veterans Follow-up (Mail) Survey, Appendix C: Lead letters/consent forms for Gulf War Follow-up Study., Appendix D: DAMD17-98-8662, Mod P0003.

# Appendix A.

Data Form for Tenth Annual Gulf War Veterans Health Survey Telephone Prompt

Project Name: TENTH ANNIVERSARY GULF WAR VETERANS HEALTH SURVEY Active Duty Sample Members

Project #: **07360.040** (1/11/02 Version)

#### **Tracing Control Form**

	Update Addre	ss/Phor	ne #	ί.	.,
Affix Label Here	Address: City: State: Phone 1: Phone 2:				

- 1. CALL ATTEMPTS # 1-4 GO TO 5 CALL ATTEMPT # 5 - CONTINUE
- 2. ANSWERING MACHINE GO TO 3 LIVE CONTACT - GO TO 4
- 3. ON THE FIFTH ATTEMPT **ONLY** PLEASE LEAVE THE FOLLOWING MESSAGE UNLESS THE VOICE MAIL GREETING INDICATES THAT YOU HAVE **NOT** REACHED THE SUBJECT'S RESIDENCE (E.G., THE SUBJECT IS BOB SMITH AND THE VOICE MAIL GREETING INDICATES THAT YOU HAVE REACHED THE DANIEL'S RESIDENCE).

Hello, this is (FULL NAME) calling on behalf of Duke University Medical Center from the Research Triangle Institute. Recently we mailed Mr/Ms (SUBJECT'S LAST NAME) a questionnaire about health issues. We are calling to make sure you got the questionnaire packet and to urge you to participate in our study. We would appreciate it if you could complete the questionnaire and send it back to us assoon as possible. If you have any questions about this research or if you have received this message in error, please call Kim Watts toll free at 800-334-8571, x7438. Ms Watts can also schedule an appointment to complete the survey over the telephone should Mr/Ms (SUBJECT'S LAST NAME) prefer. Thank you very much for your time and help with this important study.

#### CODE AS AM/ML

4. IF REMINDER PROMPT IS NOT COMPLETE BY FIFTH CALL ATTEMPT AND SUBJECT IS UNAVAILABLE, LEAVE THE FOLLOWING MESSAGE WITH ANY RESPONSIBLE PERSON WHO ANSWERS THE PHONE.

Hello, this is (FULL NAME) calling on behalf of Duke University Medical Center from the Research Triangle Institute. Recently we mailed Mr/Ms (SUBJECT'S LAST NAME) a questionnaire about health issues. We have not yet received the questionnaire back so we are calling to make sure he/she received it and to urge him/her to participate in our study. It is very important that as many people as possible participate in this project in order to gain the most accurate information we can about the health of Gulf War Veterans. We would appreciate it if he/she could complete the brown and white questionnaire and send it back to usas soon as possible. If he/she has any questions about this research, please have him/her call Kim Watts toll free at 800-334-8571, x7438. Ms Watts can also schedule an appointment for Mr/Ms (SUBJECT'S LAST NAME) to complete the survey over the telephone, should he/she prefer. Thank you very much for your time and help with this important study.

THANK PERSON AND CODE AS MSG LEFT

Project #: **07360.040** (1/11/02 Version)

5.	Hello, 1 Triangl	this is (FULL NAME) ca le Institute. May I please	lling on speak v	behalf of Duke University Medical Center from the Research with (SUBJECT)?
	IF SUE	BJECT OR KNOWLEDO BACK TIME, RECORD	EABLE IN COM	HOUSEHOLD MEMBER IS NOT AVAILABLE, DETERMINE MMENTS AND FLAG FRONT OF FORM WITH POST-IT NOTE
6.	questio	onnaire back so we are ca	lling to	tionnaire about health issues. We have not yet received the make sure you/he/she got the questionnaire packet and to determine if Did you/he/she receive the packet?
	[ ]	YES	[ ]	NO - CONFIRM MAILING ADDRESS, MAKE CHANGES AS NECESSARY AND CONTINUE
7.	Did yo	u/he/she serve in the Per	sian Gul	f Theater between August 1990 and July 1991?
	[]	YES	[]	NO - THANK AND CODE AS <b>INEL</b> (INELIGIBLE)
8.	particij Vetera Health	pate in this project in ord	er to gai	nate in our study. It is very important that as many people as possible in the most accurate information we can about the health of Gulf War u/he/she could complete the Tenth Anniversary Gulf War Veterans to you think you/he/she will be able to complete the questionnaire
		R HAS COMPLETED R WILL DO OR NOT R NEEDS A REMAIL REFUSED - THANK A	SURE - - GO TO	GO TO 9
9.	Do you	u//Does he/she still have	the ques	tionnaire we sent?
	[ ]	YES - GO TO 11 NO OR NOT SURE		
10.	correct	send you/him/her another tly. I have (READ ADD pest number at which to r	RESS F	as possible. Let me just be sure we have your address recorded ROM ABOVE - MAKE CHANGES AS NECESSARY). And what u/him/her?
11.	the pos	stage paid envelope. We	really n	CT'S LAST NAME) could complete the questionnaire and return it in eed everyone's responses to all the questions, so your/his/her g the questionnaire is very important. If you would prefer, I could a time for you/him/her to complete the survey over the telephone.
	[ ]	R WILL DO MAIL SU R WANTS A PHONE	RVEY . INTERV	- GO TO 12 VIEW - CONTINUE
	11a.	I will let the project co RECORD BELOW. T	ordinato HANK	r know of your preference. What are the best times to reach you?  AND CODE AS PHONE

We'll hope to receive your/his/her questionnaire in the next few weeks. We may call back in a few weeks if it hasn't arrived. ANSWER R'S QUESTIONS AS NEEDED - USE FACT SHEET. FOR DETAILED QUESTIONS, REFER RESPONDENTS TO: Kim Watts - 800-334-8571, x7438.

CODE AS WM, DM OR REMAIL AS APPROPRIATE

Active Duty Sample Member COMMENTS: INCLUDE A					(1) (1) (1) (1)		
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# Project Name: TENTH ANNIVERSARY GULF WAR VETERANS HEALTH SURVEY Active Duty Sample Members

Author Dialed													
Call Attempt #	1.	2.	3.	4.	5.	6.	7.	8.	9,	10.	11.	12.	
Date													
Time									·				
Result													
Interviewer ID													

RNA	-	Ring, No answer	*REF	-	Respondent indicates he/she will not
AM	-	Answering machine/voice mail; NO	*DFE/O		complete q'naire
AM/ML		message left Answering machine/voice mail;	*REF/O	-	Refusal by Other - Proxy, spouse, or other person indicates Respondent
AWINIL	-	message left			will not complete q'naire
BUSY	_	Busy signal	*INEL	_	Respondent is ineligible
DISC		Tel # Disconnected	*INCAP	-	Respondent is incapable of
FAX	-	Tel # reaches fax or modem line			completing q'naire due to mental or
CELL	-	Tel # reaches cell or mobile phone			physical impairment
*RONG	-	Wrong # to reach sample member	*TRACE	-	Tracing - call to DA, contact, etc.
*HCB	-	Hard Callback	*DEC	-	Respondent is deceased
*SCB	-	Soft Callback	*UFD	-	Respondent unavailable for duration
*RCB	-	Random Callback			of project; until after (2/1/02) and
*MSG LEF	T-	Prompt not completed by 5th call,			will not be able to complete q'naire
		message left with HH member	*SUPREV	-	Other Problem - Supervisor
*REMAIL	_	Respondent or other says			attention
		Respondent is eligible but needs	ULOC	-	Unable to locate (SUPERVISOR
		new copy of q'naire			CODE ONLY)
*DM	-	Respondent DID mail questionnaire	RECD	-	Q'naire has been received by RTI
	. 1	already			(SUPERVISOR CODE ONLY)
*WM	-	Respondent WILL mail	*MSG TRA	CE -	Message left with contact who
		questionnaire			wouldn't give Respondent's phone
*PHONE	-	Repondent prefers to complete the			(code added 1/11/02)
		survey by phone			•
		*			

<sup>\*</sup> PLEASE EXPLAIN IN COMMENTS

### Appendix B.

Gulf War Veterans Follow-up (Mail) Survey



3040 Cornwallis Road ■ PO Box 12194 ■ Research Triangle Park, NC 27709-2194 ■ USA Telephone 919 541-6000 ■ Fax 919 541-5985 ■ www.rti.org

VERSION: NONACTIVE CATI

«fname» «lname» «suffix» «addr1» «city», «state» «zip»

Study ID «caseid» Gift card: «cardno»

Dear «title» «lname»:

«date»

We need your help! You have been selected to participate in the Gulf War Veterans Follow-up Interview, a research study being conducted by Duke University Medical Center and RTI International, a non-profit research organization. The goal of the study is to learn more about the health of Gulf War veterans who were unable to complete a mail survey.

Although we realize that there are many demands for your time, your participation is critical to the success of this important study. We are conducting these interviews because of concerns that the health of veterans who completed the mail survey may be different from those who were unable to. It is only through your participation that we can ensure that the results of this research accurately represent the experiences of *all* Gulf War veterans.

Participating is easy! In the near future, a professionally trained interviewer from RTI will be calling you to complete a telephone interview. The interview includes questions about your military history, physical health, emotional well-being, and current life circumstances. It will take approximately 25 minutes. As a token of our appreciation, we have enclosed a \$5 Target gift card. *Please hold on to this card*! When you complete your telephone interview, we will increase the amount of your gift card by \$30.

Your participation is completely voluntary and will in no way affect health care or other benefits that you are entitled to. Although it is possible that some questions could make you a little uncomfortable, you may decline to answer any question or stop at any time. Please be assured that both Duke and RTI follow strict confidentiality procedures to protect the information collected and the privacy of study participants. No information that could link you to your answers will ever be released. Any results that are reported from this study will refer to group data only.

If you would prefer to complete the interview now or would like schedule an interview at a time that is convenient for you, just call us toll free at 1-866-309-4556. If your current telephone number is not «phone», please take a few minutes to call 1-866-309-4556 so that we can correct our records. Also, please call us at 1-866-309-4556 if you have a service or device that screens your calls such as privacy manager so that you can complete the study interview at your convenience. When you call, you will need to provide the Study ID number printed in the top right corner of this letter. If you have any questions about the study, you may contact Kim Watts at RTI toll free at 1-800-334-8571, x7438 or by e-mail at watts@rti.org. If you have questions about your rights as a research subject, you may call RTI's Human Protection's Office at 1-866-214-2043 (a toll free number).

Thank you for your time and help with this important research.

Sincerely,

**BEST AVAILABLE COPY** 

John A. Fairbank, Ph.D. Associate Professor of Medical Psychology Duke University Medical Center

Lori Ebert, Ph.D.
Project Director, Gulf War Veterans Health Study
RTI International

#### **GULF WAR INFORMATION SOURCES**

Toll-free information lines:
1-800-796-9699 (for current active duty military personnel)
1-10800-7749-8387 (for other Gulf War, Veterans)

Informational sites on the World Wide Web: http://www.va.gov/health/environ/persgult.htm http://www.gultlink.ord.mil/medical/#chide.



3040 Cornwallis Road ■ PO Box 12194 ■ Research Triangle Park, NC 27709-2194 ■ USA Telephone 919 541-6000 ■ Fax 919 541-5985 ■ www.rti.org

VERSION: ACTIVE DUTY CATI

«fname» «lname» «suffix» «addr1» «city», «state» «zip»

Study ID «caseid»

Dear «title» «lname»:

«date»

We need your help! You have been selected to participate in the Gulf War Veterans Follow-up Interview, a research study being conducted by Duke University Medical Center and RTI International, a non-profit research organization. The goal of the study is to learn more about the health of Gulf War veterans who were unable to complete a mail survey.

Although we realize that there are many demands for your time, your participation is critical to the success of this important study. We are conducting these interviews because of concerns that the health of veterans who completed the mail survey may be different from those who were unable to. It is only through your participation that we can ensure that the results of this research accurately represent the experiences of *all* Gulf War veterans.

Participating is easy! In the near future, a professionally trained interviewer from RTI will be calling you to complete a telephone interview. The interview includes questions about your military history, physical health, emotional well-being, and current life circumstances. It will take approximately 25 minutes.

Your participation is completely voluntary and will in no way affect health care or other benefits that you are entitled to. Although it is possible that some questions could make you a little uncomfortable, you may decline to answer any question or stop at any time. Please be assured that both Duke and RTI follow strict confidentiality procedures to protect the information collected and the privacy of study participants. No information that could link you to your answers will ever be released. Any results that are reported from this study will refer to group data only.

If you would prefer to complete the interview now or would like schedule an interview at a time that is convenient for you, just call us toll free at 1-866-309-4556. If your current telephone number is not «phone», please take a few minutes to call 1-866-309-4556 so that we can correct our records. Also, please call us at 1-866-309-4556 if you have a service or device that screens your calls such as privacy manager so that you can complete the study interview at your convenience. When you call, you will need to provide the Study ID number printed in the top right corner of this letter. If you have any questions about the study, you may contact Kim Watts at RTI toll free at 1-800-334-8571, x7438 or by e-mail at watts@rti.org. If you have questions about your rights as a research subject, you may call RTI's Human Protection's Office at 1-866-214-2043 (a toll free number).

Thank you for your time and help with this important research.

Sincerely,

John A. Fairbank, Ph.D. Associate Professor of Medical Psychology Duke University Medical Center

Lori Ebert, Ph.D. Project Director, Gulf War Veterans Health Study RTI International

#### **GULF WAR INFORMATION SOURCES**

Toll-free information lines:

1-800-796-9699 (for current active duty military personnel)

1-800-749-8387 (for other Gulf War Veterans)

Informational sites on the World Wide Web: http://www.va.gov/health/environ/persgult.htm http://www.gulflink.osd.mil/medical/#cbid

turning knowledge into practice

RTI International is a tradename of Research Triangle Institute



3040 Cornwallis Road = PO Box 12194 = Research Triangle Park, NC 27709-2194 = USA Telephone 919 541-6000 = Fax 919 541-5985 = www.rti.org

VERSION: ACTIVE DUTY MAIL SURVEY

«fname» «lname» «suffix» «addr1» «city», «state» «zip»

Study ID «caseid»

Dear «title» «lname»:

«date»

We need your help! You have been selected to participate in the Gulf War Veterans Follow-up Interview, a research study being conducted by Duke University Medical Center and RTI International, a non-profit research organization. The goal of the study is to learn more about the health of Gulf War veterans who were unable to complete an initial mail survey about this topic.

Although we realize that there are many demands for your time, your participation is critical to the success of this important study. We are conducting these interviews because of concerns that the health of veterans who completed the initial mail survey may be different from those who were unable to. It is only through your participation that we can ensure that the results of this research accurately represent the experiences of *all* Gulf War veterans.

Participating is easy! You can complete the survey included with this letter and return it using the enclosed reply envelope or if you prefer you can complete the survey over the phone. *Just call RTI toll free at 1-866-309-4556* and give the interviewer the Study ID number printed in the top right hand corner of this letter. The survey includes questions about your military history, physical health, emotional well-being, and current life circumstances. It will take approximately 25 minutes.

Your participation is completely voluntary and will in no way affect health care or other benefits that you are entitled to. Although it is possible that some questions could make you a little uncomfortable, you may decline to answer any question or stop at any time. Please be assured that both Duke and RTI follow strict confidentiality procedures to protect the information collected and the privacy of study participants. No information that could link you to your answers will ever be released. Any results that are reported from this study will refer to group data only.

To complete the survey by telephone, call 1-866-309-4556. If you have questions about the study, please call Kim Watts at RTI toll free at 1-800-334-8571, x7438 or send her an e-mail at <a href="watts@rti.org">watts@rti.org</a>. If you have questions about your rights as a research subject, you may call RTI's Human Protection's Office at 1-866-214-2043 (a toll free number).

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3040 Cornwallis Road ■ PO Box 12194 ■ Research Triangle Park, NC 27709-2194 ■ USA Telephone 919 541-6000 ■ Fax 919 541-5985 ■ www.rti.org

#### VERSION: NONACTIVE MAIL SURVEY

«fname» «lname» «suffix» «addr1» «city», «state» «zip»

Study ID «caseid» Gift card: «cardno»

Dear «title» «lname»:

«date»

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As a token of our appreciation, we have enclosed a \$5 Target gift card. *Please hold on to the card*! Once you we receive your completed survey or you complete the survey over the phone, we will increase the amount of your gift card by \$30.

Your participation is completely voluntary and will in no way affect health care or other benefits that you are entitled to. Although it is possible that some questions could make you a little uncomfortable, you may decline to answer any question or stop at any time. Please be assured that both Duke and RTI follow strict confidentiality procedures to protect the information collected and the privacy of study participants. No information that could link you to your answers will ever be released. Any results that are reported from this study will refer to group data only.

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## Appendix C.

Lead Letters/Consent Forms for Gulf War Follow-up Survey









# Gulf War Veterans Follow-up Survey

Conducted by:

Duke University Medical Center RTI

The purpose of this questionnaire is to find out more about the current health of veterans who served in the Persian Gulf Theater at any time from August 1990 through July 1991.

If you were not deployed to the Persian Gulf Theater at all during that time period, please place an "x" in the box below and return the questionnaire now in the envelope provided. We do not need you to answer any of the questions, but it is very important that you return the questionnaire to us so that we will know that you were not deployed during that time.

☐ I was not deployed to the Persian Gulf Theater at any time from August 1990 through July 1991.

If you were deployed to the Persian Gulf Theater at any time from August 1990 through July 1991, please complete the questionnaire.

# **Gulf War Veterans Follow-up Survey Instructions**

- Pay careful attention to the *time frames* in questions and in the instructions that appear before some groups of questions. The time frames change from section to section of the questionnaire. For example, some questions will refer to your experiences during the past 6 months whereas others will ask about the past 4 weeks.
- Most questions provide a set of answers. Read *all* of the printed answers before making your choice. If none of the printed answers exactly applies to you, put an "x" in the box next to the one answer that *best* fits your situation.
- Either a pen or pencil may be used to complete this questionnaire.
- When answering questions that require marking a box, please use an "x."
- If you need to change an answer, please make sure that your old answer is either completely erased or clearly crossed out.
- Sometimes you will be asked to "Choose an answer *on each line*," for example, when you are asked, "Please choose 'Yes' or 'No' for each question." For these questions, record an answer to <u>each part</u> of the question, as shown:

# EXAMPLE: Has a health care provider ever told you that you had any of the following? A. ASTHMA B. CHRONIC BRONCHITIS C. CHRONIC RHINITIS OR HAY FEVER

■ For many questions, you will be asked to "Please choose the **best** answer." You should mark only **one** box for your answer in the column below the question, as shown:

# EXAMPLE: In general, would you say your health is? (Please choose the best answer) Excellent Very good Good Fair Poor

1. From August 1990 through July 1991, in which area(s) of the Persian Gulf Theater did you serve? (Please choose "No" or "Yes" for each area.)	4. From August 1990 through July 1991, in which component of the Military did you serve?  (Please choose the best answer.)
A. IRAQ B. SAUDI ARABIA C. KUWAIT D. TURKEY E. OMAN F. BAHRAIN G. QATAR H. THE UNITED ARAB EMIRATES I. THE GULF OF OMAN K. THE GULF OF ADEN L. THE ARABIAN SEA  2. During the 12 months from August 1990 through July 1991, about how much time did you spend in the Persian Gulf Theater? (Please choose the best answer.) LESS THAN 3 MONTHS 3 MONTHS BUT LESS THAN 6 MONTHS MORE THAN 9 MONTHS MORE THAN 9 MONTHS WHO THAN 9 MONTHS IRAQ SAUDI ARABIA KUWAIT TURKEY OMAN BAHRAIN QATAR THE UNITED ARAB EMIRATES THE GULF OF OMAN THE GULF OF OMAN THE GULF OF OMAN THE GULF OF OMAN THE GULF OF ADEN THE ARABIAN SEA OTHER. WHERE? (PLEASE SPECIFY)	ACTIVE ARMY (USA)  ARMY NATIONAL GUARD (ARNG)  ARMY RESERVE (USAR)  ACTIVE NAVY (USN)  NAVAL RESERVE (USAF)  AIR NATIONAL GUARD (ANG)  AIR FORCE RESERVE (USAFR)  ACTIVE MARINE CORP (USMC)  MARINE CORPS RESERVE (USMCR)  COAST GUARD (USCG)  5. What date did you first begin serving in the Persian Gulf Theater, even if it was before August 1990?  MONTH YEAR  MONTH YEAR  MONTH YEAR  MONTH YEAR  Theater, even if it was after July 1991, (that is, what was the end date of your last deployment to the Persian Gulf)?  MONTH YEAR  TO What was your pay grade from August 1990 through July 1991 during the time period that your were in the Persian Gulf Theater?  (Please choose the best answer.)  Enlisted Officer  E-1 TRAINEE  B-2 WI-W5  B-3 O-1 OR O-1E  B-4 O-2 OR O-2E  B-5 O-3 OR O-3E  B-6 O-4  B-7 O-5  B-8 O-6
	⊔ E-9 □ О-7 то О-10

1

The next group of questions ask about a number of health problems or concerns a person might have. We would like to know whether or not you have experienced each of these problems during the <u>past 6 months</u>.

8. In the <u>past 6 months</u>, have you experienced any of these health problems? (Please choose "No" or "Yes" for each health problem.)

_No S Yes≥
A. Severe arthritis, rheumatism,
OR OTHER BONE OR JOINT DISEASES
В. Asthма
C. Bronchitis
D. EMPHYSEMA OR OTHER LUNG DISEASES
E. AIDS
F. BLINDNESS OR SEVERE VISUAL OR
HEARING IMPAIRMENT
G. HIGH BLOOD PRESSURE OR HYPERTENSION
H. DIABETES OR HIGH BLOOD SUGAR
I. HEART ATTACK OR OTHER SERIOUS
HEART TROUBLE
J. SEVERE HERNIA OR RUPTURE
K. SEVERE KIDNEY OR LIVER DISEASE
L. Lupus, thyroid disease, or other
AUTOIMMUNE DISORDERS
M.MULTIPLE SCLEROSIS, EPILEPSY,
OR OTHER NEUROLOGICAL DISORDERS
N. CHRONIC STOMACH OR GALL BLADDER
TROUBLE
O. STROKE
P. ULCER
Q. LEUKEMIA
R. OTHER CANCER OR A MALIGNANT TUMOR
OF ANY KIND
S. APLASTIC ANEMIA
T. ALLERGIES OR HAY FEVER
U. ANY DISEASE OF THE GENITAL ORGANS
V. MIGRAINE HEADACHES
W.Fibromyalgia, fibrostitis, or myofascial pain syndrome
X. Ear infections
Y. ECZEMA, PSORIASIS, OR DERMATITIS
Z. OTHER MAJOR HEALTH PROBLEMS
IF "YES," WHAT WERE THESE HEALTH PROBLEMS?
IF 1ES, WHAT WERE THESE HEADTH TROOPERS.

Next we would like to know whether or not you have had <u>persistent or recurring</u> difficulties with other healh problems or concerns <u>throughout the past 6</u> <u>months or longer</u>.

For question 9, if you have had a problem either every-day or off-and-on throughout the past 6 months or longer, choose 'Yes' as your response in Column 1. Then in Column 2, indicate whether or not you ever had the problem before you were deployed to the Gulf War, that is before you were deployed to the Persian Gulf Theater during the period from August 1990 to July 1991. If you have not had a problem throughout the past 6 months, choose 'No' as your response in Column 1 and go on to the next problem. That is, if you choose 'No' in Column 1, you do not need to complete Column 2 for that problem only.

	nths, have you had				
-	sistent or recurring	COLU	MN L	COLU	MIN
	blems with	Had p	ast 6	Had b	efore
•	ease choose "No"	mont		deploy	
or "	'Yes" for each health	lon		Gulf	
pro	blem.)	No .	Yes	No	Yes
A.	HOT OR COLD SPELLS, FEVER,				
	SWEATS AT NIGHT, OR SHAKING				
	CHILLS	닏	∐.•	ᅵ닏ㅣ	<u> </u>
В.	MOUTH SORES		□ •		L
C.	INFLAMMATION OR REDNESS		L1 *		
	OF YOUR EYES (PINK EYES)	ᅵ片	.	ᅵ님ㅣ	늗
D.	UNEXPECTED HAIR LOSS		├  ₹	ᅵᅱ	<u> </u>
E.	SORE THROAT OR IRRITATION				L-
F.	PAIN OR ACHES IN MORE THAN				
_	ONE JOINT				-
G.	BACK PAIN			ΙĦ	
Η.	JOINT STIFFNESS	''	- 7		-
I.	MUSCLE TENSION, ACHES, SORENESS, OR STIFFNESS				
J.	FEELING WEAK IN PARTS OF		,	_	-
J.	YOUR BODY				
K.	TENDER OR PAINFUL LYMPH				
11.	GLANDS UNDER YOUR ARMS				
	OR IN YOUR NECK OR GROIN				ŀ [
L.	A FEELING OF BODILY		l	]	l _
	DISCOMFORT AFTER EXERTION				L
M.	NUMBNESS OR TINGLING IN	l _	_		_ ا
	PARTS OF YOUR BODY				L
N.	Loss of hearing or ringing		l		_
	IN YOUR EARS			기님	1 -
O.	TREMORS OR SHAKING			<b>'</b>    -	

(continued on next page)

mo per	roughout the past 6 nths, have you had sistent or recurring blems with	Had mon lor	MN I past 6 ths or iger	Had l deploy Gulf	oefore yed to War	Throughout the past 6 months, have you had persistent or recurring problems with  COLUMN 1 COLUMN 2 Had past 6 months or deployed to Gulf War No Yes No Yes
P.	DOUBLE VISION, WHEN YOU SEE					SS. FEELING UNREFRESHED AFTER
	2 IMAGES, NOT CORRECTABLE					SLEEP
	BY GLASSES			П	П	TT. Cough
Q.	SEIZURES OR CONVULSIONS					UU. WHEEZING.
R.	ANY HEADACHES					VV. SHORTNESS OF BREATH.
S.	HEART PALPITATIONS, POUNDING					WW. Unusual Physical discomfort
	OR RACING					IN YOUR GENITALS DURING OR
T.	PAINS IN YOUR HEART OR CHEST					AFTER INTERCOURSE
U.	FAINTNESS, LIGHTHEADEDNESS					
	OR DIZZINESS OR TROUBLE					10. In the past 6 months, has your sexual
V.	MAINTAINING BALANCE					partner(s) complained of unusual physical
W.	TROUBLE SWALLOWING NAUSEA OR AN UPSET STOMACH					discomfort during or after sexual intercourse?
**.	(OTHER THAN DURING					
	PREGNANCY)					☐ YES
X.	REFLUX, HEARTBURN, GAS OR		*			□ No
	INDIGESTION (OTHER THAN					HAVE NOT HAD INTERCOURSE IN THE PAST 6 MONTHS
	DURING PREGNANCY)					11. In the past 6 months (Please choose
Y.	VOMITING (OTHER THAN		- 7	_	_	"No" or "Yes" for each question.)
	DURING PREGNANCY)					
Z.	FREQUENT DIARRHEA (MORE				_	No Yes
	THAN 3 WATERY STOOLS PER DAY)					A. HAVE YOU HAD PROBLEMS WITH
AA.	ABDOMINAL PAIN			***************************************		FEELING TIRED?
	(OTHER THAN WHEN				_	B. HAVE YOU NEEDED TO REST MORE?
DD	MENSTRUATING)					SLEEPY OR DROWSY?
	CONSTIPATION				HI	D. HAVE YOU HAD PROBLEMS STARTING
	FREQUENT OR PAINFUL URINATION ANY TENDENCY TO BRUISE OR				$\sqcup$	THINGS?
טט.	BLEED EASILY (INCLUDING NOSE			***************************************		E. WERE YOU LACKING IN ENERGY?
	BLEEDING)				$\neg 1$	F. HAVE YOU HAD LESS STRENGTH
EE.	SKIN REDNESS OR A SKIN RASH .			H	H1	IN YOUR MUSCLES?
	DRYNESS OR SCALING OF YOUR			_	7	G. HAVE YOU BEEN FEELING WEAK?
	SKIN					H. HAVE YOU HAD PROBLEMS THINKING
GG.	BLISTERS, OPEN SORES, OR SKIN					CLEARLY?
	ULCERS					I. HAVE YOU BEEN MAKING SLIPS OF THE
HH.	ERUPTIONS OF HIVES OR WELTS		_			TONGUE WHEN SPEAKING?
TT	ON YOUR SKIN					J. HAVE YOU HAD PROBLEMS WITH YOUR
II.	PERSISTENT SENSATIONS OF		-1		$\neg$ $\Box$	MEMORY?
JJ.	ITCHING ON YOUR SKIN					FORGETFULNESS (LIKE FORGETTING
JJ.	WOUNDS THAT ARE SLOW TO HEAL	П		$\sqcap^{1}$	$\neg 1$	WHERE YOU PUT THINGS OR FORGETTING
KK.	SWELLING OF BOTH FEET		└ <b>*</b>		$\sqcup$	APPOINTMENTS)?
	OR BOTH ANKLES	П			$\neg 1$	L. HAVE YOU HAD ANY DIFFICULTY
LL.	SINUS PROBLEMS/RHINITIS	П	Hil	H	ĦΙ	COMPREHENDING OR UNDERSTANDING
	.Unintended weight gain of					WHAT OTHERS ARE SAYING TO YOU?
	10 LBS OR MORE					M. HAVE YOU HAD PROBLEMS WITH FEELING
NN.	Unintended weight loss of	0,010		-		CONFUSED OR DISORIENTED IN PLACE OR
	10 LBS OR MORE					TIME? (FEELING CONFUSED ABOUT WHERE
	FEELING ANXIOUS OR NERVOUS.					YOU ARE, WHO IS AROUND, OR NOT
	FEELING DEPRESSED					KNOWING WHAT DAY IT IS)
	FEELING MOODY OR IRRITABLE.					N. HAVE YOU BEEN HAVING DIFFICULTY
KK.	TROUBLE FINDING WORDS					UNDERSTANDING WHAT YOU READ, EVEN
	1					WHEN YOU ARE PAYING ATTENTION TO WHAT YOU ARE READING?
						TOO ARE READING!

12. In the past 6 months, have you experienced	G. Have you fully recovered from your fatigue?
extreme fatigue almost every day for 1 month	$\square$ No $\rightarrow$ Go to Question 13
or longer?	
A. $\square$ No $\rightarrow$ GO TO QUESTION 13	$\square$ YES $\hookrightarrow$ In what month and year did you recover?
YES  → IN WHAT MONTH AND YEAR DID THIS FIRST BEGIN,	
EVEN IF IT BEGAN PRIOR TO THE PAST 6 MONTHS?	H. MONTH YEAR
B. MONTH YEAR	
	13. In the past 6 months, has routine or normal
	exposure to substances like gasoline, hair
C. Did this fatigue begin with	spray, paint, household cleaners, perfume,
C. Did this latigue begin with  Don't	or soap caused you to feel physically ill?
No Yes know	A. $\square$ No $\rightarrow$ Go to Question 14
1. A COLD OR FLU-LIKE ILLNESS?	Yes
2. Mononucleosis?	In what month and year did this first begin,
3. Another infection?	EVEN IF IT BEGAN PRIOR TO THE PAST 6 MONTHS?
A AN EMOTIONALLY STRESSELL	B. MONTH YEAR
OR OTHER EVENT?	
D. We would like you to rate this fatigue.	14. During the past 6 months, how many physical
Think of a scale from 0 to 10. A 0 means	problems have you had that have not been
your energy level was extremely low, and a	adequately understood or expained by your
10 means it was extremely high. Think now	doctor? (Please choose the best answer.)
of the worst part of your fatigue. What was	☐ None
the lowest that your energy level dropped?	
O ZERO 4 FOUR 8 EIGHT	
ONE 5 FIVE 9 NINE	3 or more
2 Two 6 Six 10 Ten	
3 THREE 7 SEVEN	
	The next few questions ask about your health, <u>now</u>
E. During the worst part of your fatigue,	and during the past 4 weeks.
what percent of your usual daily activity	
were you able to maintain?	15. In general, would you say your health is
Less than 25%	(Please choose the best answer.)
<ul><li>☐ 25 UP TO 50%</li><li>☐ 50 UP TO 75%</li></ul>	EXCELLENT
☐ 75% OR MORE	☐ VERY GOOD ☐ GOOD
	☐ FAIR
F. Did you see a doctor specifically for your	Poor
fatigue?	
YES	16. During the past 4 weeks, have you had to cut
□ No	down on the amount of time you spent on
	work or other activities as a result of your
	physical health?
	Yes
	□ No

17. During the past 4 weeks, have you accomplished less than you would like, as a result of your physical health?  YES NO  18. During the past 4 weeks, were you limited in the kind of work or other regular daily activities you do, as a result of your physical health?  YES NO  Below is a list of problems people sometimes have. Pleat that best describes how much that problem has distresse	cul dai phy effo —	ring the past 4 ty performing ly activities yo ysical health, fo ort? YES NO	the wor u do as or exam	k or othe a result o ple, it too	r regular f your k extra
During the past 4 weeks, how much were you bother		Not at all	A <u>little</u>	Quite  a bit	Extremely
20. Loss of sexual interest or pleasure		1	2	3	4
21. FEELING LOW IN ENERGY OR SLOWED DOWN		1	2	3	. 4
22. POOR APPETITE		1	. 2	3	4
23. CRYING EASILY			2	3	, 4
24. A FEELING OF BEING TRAPPED OR CAUGHT		1	2	3	4
25. Blaming yourself for things		1	2	3	4
<b>26.</b> FEELING LONELY		1	2	3	4
27. FEELING BLUE			2	3	4
28. Worrying or stewing about things		1	2	3	4
29. FEELING NO INTEREST IN THINGS			2	3	4
30. DIFFICULTY IN FALLING ASLEEP OR STAYING ASLEEP	C.155k. , (13000000000000000000000000000000000000		2	3	. 4
31. FEELING HOPELESS ABOUT THE FUTURE			2	3	4
32. FEELING EVERYTHING IS AN EFFORT	gergen for Anna and	The second of the confidence of the second decrees	2	3	4
33. FEELINGS OF WORTHLESSNESS			2	3	4

Below is a list of problems and complaints that people sometimes have in response to stressful life experiences. These questions ask about responses you may have had to a stressful Gulf War experience. By "stressful Gulf War experience" we mean an experience you had during your service in the Persian Gulf between August 1990 and July 1991. Please read each question carefully, then mark the box to the right that best decribes how much you have been bothered by that problem in the past 6 months.

Time during the

	E220 - 12-50	past	J. Shires	onths	- TEN HER TOOM
	Not at all	А шттв вп	MODERATELY	Оитте А вт	EXTREMELY
In the past 6 months, how much have you been bothered by:	4or 4	A LITT	Мор	E	EXTR
34. Repeated, disturbing memories, thoughts, or images of a stressful Gulf War experience?	1	2		4	
35. Repeated, disturbing <u>dreams</u> of a stressful Gulf War experience?		2	3	4	5
36. Suddenly acting or feeling as if a stressful Gulf War experience were happening again (as if you were reliving it)?	1	2	3	4	5
37. Feeling <u>very upset</u> when <u>something reminded you</u> of a stressful Gulf War experience?	ı	2	3	4	5
38. Having <u>physical reactions</u> (e.g., heart pounding, trouble breathing, sweating) when <u>something reminded</u> you of a stressful Gulf War experience?	1	2	3	4	5
39. Avoiding thinking about or talking about a stressful Gulf War experience or avoiding having feelings related to it?	1	2	3	4	5
40. Avoiding <u>activities or situations</u> because <u>they reminded you</u> of a stressful Gulf War experience?		2	3	4	5
41. Trouble remembering important parts of a stressful Gulf War experience?	1	2	3	4	5
42. Loss of interest in activities that you used to enjoy?	1	2	3	4	5
43. Feeling distant or cut off from other people?	1	2	3	4	5
44. Feeling emotionally numb or being unable to have loving feelings for those close to you?	1	2	3	4	5
45. Feeling as if your <u>future</u> somehow will be <u>cut short</u> ?	1	2	3	4	5
46. Trouble falling or staying asleep?	1	2	3	4	5
47. Feeling <u>irritable</u> or having <u>angry outbursts</u> ?	1	2	3	4	5
48. Having difficulty concentrating?	1	2	3	4	5
49. Being "superalert" or watchful or on guard?		2	3	4	5
50. Feeling jumpy or easily startled	1	2	3	4	5

alcoi	next few questions ask about use of tobacco and hol.	55.	Currently, in which component of the Military do you serve? (Please choose the
<b>E</b> 1	Would you consider yourself a fermion		best answer.)
51.	Would you consider yourself a former smoker, a current smoker, or someone who never smoked?    Former smoker   Current smoker   Never smoked		I DO NOT CURRENTLY SERVE IN THE MILITARY ACTIVE ARMY (USA) ARMY NATIONAL GUARD (ARNG) ARMY RESERVE (USAR) ACTIVE NAVY (USN) NAVAL RESERVE (USNR)
52.	How often do you have a drink containing alcohol?  ☐ Never → GO TO QUESTION 54 ☐ MONTHLY OR LESS ☐ TWO TO FOUR TIMES A MONTH ☐ TWO TO THREE TIMES PER WEEK ☐ FOUR OR MORE TIMES A WEEK	56.	Active Air Force (USAF) Air National Guard (ANG) Air Force Reserve (USAFR) Active Marine Corp (USMC) Marine Corps Reserve (USMCR) Coast Guard (USCG)  What is your current marital situation? (Please choose the best answer.)
53.	How many drinks containing alcohol do you have on a typical day when you are drinking? In answering, count as a drink a can or bottle of beer, a wine cooler, a glass of wine, champagne or sherry, a shot of liquor, or a mixed drink or cocktail.  1 OR 2 3 OR 4 5 OR 6	57.	Not married, but living as married Married Separated and not living as married Divorced and not living as married Widowed and not living as married Single, never married, and not living as married as married What is the month, day, and year of your birth?
	☐ 7 OR 9 ☐ 10 OR MORE		MONTH DAY YEAR
in ge	next few questions ask about your work and life eneral.  Which of the following best describes your	58.	Are you male or female? ☐ Male ☐ Female
	current work situation? (Please choose the best answer.)  Working for pay (INCLUDES ACTIVE-DUTY MILITARY)  Have a Job, but not working (BECAUSE OF MATERNITY LEAVE, BAD WEATHER, STRIKE, SEASONAL WORK, TEMPORARY LAYOFF, ETC.)  UNEMPLOYED OR PERMANENTLY LAID OFF AND LOOKING FOR WORK  UNEMPLOYED OR PERMANENTLY LAID OFF	59.	Are you of Spanish or Hispanic origin or descent? (Please choose the best answer.)  No (not Spanish or Hispanic) Yes, Puerto Rican Yes, Mexican or Mexican-American or Chicano Yes, Cuban Yes, Cuban Yes, Central or South American Yes, other Spanish or Hispanic origin
	AND NOT LOOKING FOR WORK  KEEPING HOUSE FULL-TIME  IN SCHOOL OR TRAINING PROGRAM  RETIRED  DISABLED	60.	Which of these categories best describes you?  American Indian/Eskimo/Aleut Black/African-American Asian/Chinese/Japanese/Korean/ Filipino/Indian/Pacific Islander White/Caucasian

gath veter infor	What is your highest level of education now?  (Please choose the best answer.)    HAVE NOT YET GRADUATED FROM HIGH SCHOOL   GED OR ABE CERTIFICATE   HIGH SCHOOL GRADUATE   TRADE OR TECHNICAL SCHOOL GRADUATE   SOME COLLEGE BUT NOT A 4-YEAR DEGREE   4-YEAR COLLEGE DEGREE (BA, BS, OR EQUIVALENT)   GRADUATE OR PROFESSIONAL STUDY BUT NO GRADUATE DEGREE   GRADUATE OR PROFESSIONAL DEGREE    MEXT two questions ask about income. We are earing this information to understand if and how rans' health affects their earnings. As with all mation you provide on this survey, your answers ese questions are kept confidential.    During the past 12 months, approximately how much income before taxes and deductions did you personally earn from jobs or other employment (including self-employment)? Please, only include money from wages, salaries, tips, or bonuses that you received while working for pay.   O - \$4,999   \$5,000 - \$9,999   \$10,000 - \$14,999   \$50,000 - \$29,999   \$30,000 - \$33,999   \$40,000 - \$49,999   \$55,000 - \$99,999   \$100,000 - \$149,999   \$55,000 - \$99,999   \$150,000 - \$74,999   \$75,000 - \$99,999   \$150,000 - \$149,999   \$150,000 - \$200,000   MORE THAN \$200,000	64.	During the past 12 months, approximately how much income before taxes and deductions was received by all family members who live with you? Please include not only money from wages, tips, and bonuses, but also social security, retirement income, unemployment or disability payments, public assistance, etc. Also include income from interest, dividends, net income from business, farm, or rent, and any other money income your family received.    0 - \$4,999

	Please mark the box next to the description that best describes your current situation:	T
	☐ I CURRENTLY RESIDE IN THE U.S. AND EXPECT TO BE RESIDING IN THE U.S. FOR AT LEAST THE NEXT 6 MONTHS.	6
	☐ I CURRENTLY RESIDE IN THE U.S. BUT DO NOT EXPECT TO BE RESIDING IN THE U.S. FOR AT LEAST 6 MONTHS.	
	☐ I AM CURRENTLY RESIDING OUTSIDE THE U.S. BUT EXPECT TO RETURN TO THE U.S. WITHIN THE NEXT 6 MONTHS AND HAVE INCLUDED MY PERMANENT HOME PHONE NUMBER.	6
	☐ I AM CURRENTLY RESIDING OUTSIDE THE U.S. BUT EXPECT TO RETURN TO THE U.S. WITHIN THE NEXT 6 MONTHS AND DO NOT HAVE A PERMANENT HOME PHONE NUMBER.	
65 .	The Tenth Anniversary Gulf War Veterans Health Survey was a 21 page survey about veterans' health and Gulf War experiences. Do you remember receiving a copy of this survey in the mail between September 2001 and February 2002?  YES No	
66.	☐ Not sure  Please enter today's date below.	6
	MONTH DAY YEAR	
	STOP	

his section asks questions about women's health ssues. 7. During the past 6 months, have you had cramps or pain during menstrual periods requiring medication or time off from work? ☐ YES ☐ No ☐ HAVE NOT MENSTRUATED DURING PAST 6 MONTHS 8. A Pap smear is when a health care provider inserts a swab into your vagina to scrape cells from the cervix. Have you ever had a Pap smear where the result was NOT normal? A.  $\square$  Never had a Pap smear  $\rightarrow$  go to Question 68  $\square$  No  $\rightarrow$  GO TO QUESTION 68  $\square$  Don't know  $\rightarrow$  *Go to Question 68* BEFORE YOUR FIRST DEPLOYMENT, HAD YOU EVER HAD A PAP SMEAR WHERE THE RESULT WAS NOT NORMAL? B. No ☐ YES 9. Since the time of your first deployment, have you or a health care provider ever found a lump or other abnormality in your breast? A. No ☐ BEFORE YOUR FIRST DEPLOYMENT, HAD YOU EVER HAD A LUMP OR ABNORMALITY IN YOUR BREAST? B. No

☐ YES

Sometimes when people have participated in a study like the Gulf War Veterans Follow-up Study, they are interested in following up on some of the issues that they have been asked about in the study with someone who is professionally trained to deal with these kinds of issues. There are many resources available to military personnel who served during the Persian Gulf War. Below, we have provided two toll-free numbers and two Internet addresses for resources that provide a wide variety of information about Persian Gulf War veteran programs and services. Information available through these sources ranges from providing answers to veterans' frequently asked questions, to information on the treatment services (including mental health and physical health services) that are available in your area. These numbers and Internet addresses are also provided in the introductory letter that came with this questionnaire.

#### **Toll-Free Numbers**

For current active-duty military personnel—Department of Defense Persian Gulf Veterans Hotline:

1-800-796-9699

For other Gulf War veterans—VA Persian Gulf Information Helpline:

1-800-PGW-VETS (or 1-800-749-8387)

#### Internet Addresses for Informational Sites on the World Wide Web

http://www.va.gov/health/environ/persgulf.htm http://www.gulflink.osd.mil/medical/#cbid

2

Thank you for participating in this study.